

Iowa EHDI News

Your Sound Source for Early Hearing Detection & Intervention Information

Spring 2016

The EHDI World

During the annual national EHDI meeting, Iowa was awarded with the Website of the Year Award. This award is given to the most comprehensive website of all EHDI programs. Also receiving an award this year for a student poster, was Julia Omtvedt from the University of Iowa. The poster outlined research on breaking news to parents after a child is diagnosed with hearing loss.



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Rollout of INSIS:

Iowa Newborn Screening Information System (INSIS) is a NEW integrated, web-based data system that serves as the statewide tracking and surveillance system for children from birth to age 3 for all newborn screening programs in Iowa. These programs are; EHDI, Critical Congenital Heart Disease (CCHD) and Dried Blood Spot. As you know, EHDI completed trainings in May for the INSIS roll out. Supporting information has been posted in the EHDI website at <https://www.idph.iowa.gov/ehdi/database>. If you have any questions that come up, don't hesitate to contact EHDI staff.

NANI: Program Highlight

On May 11, 2016, Broadlawns Medical Center in Des Moines became the first birthing facility in Iowa to establish an interface between their electronic health records (EHR) and the Iowa Newborn Screening Information System (INSIS). Broadlawns' information technology and birth center nursing staff worked with OZ Systems to implement OZ's NANI tool – the Newborn Admission Notification Information electronic interface. This interface will allow for efficient reporting of newborns' expanded admission, discharge and transfer (ADT) information by "pulling" information from the baby's EHR and electronically recording it in INSIS. This reduces data entry errors, decreases manual data entry, and lessens the risk of duplicates. It also allows for timelier reporting of the newborn's ADT status.

Kudos to Broadlawns Medical Center for implementing this important interface! We appreciate all you do for Iowa's newborns.

NANI/Importing

With implementation of the integrated data system, EHDl will move away from manual data entry into the system. By December 31, 2016 there will be two options to move information automatically into INSIS.

One of the options is importing. To import, you will have to work with your IT department to create a flat file. This file will pull the demographic information from your file into the database. Tammy has sent information in the past about how to set up your import map. If you need her to send it to you again, please email her at tammy.ohollearn@idph.iowa.gov.

The other option is to purchase the Newborn Admission Notification Information (NANI) tool from OZ. NANI is an application that accepts and processes ADT messages that contain demographic (contact) information about newborn patients. The contact information is used to follow-up with a newborn's family about next steps. It is critical that the contact information be as complete and accurate as possible when the outreach takes place. NANI outperforms human data entry in two measurable ways: it works during labor shortages and outages, and it gathers even the most up-to-date information available for the patient's family. Addresses and phone numbers are not infrequently updated after a patient is discharged, and if that new information is shared with your facility, NANI will receive and process it. All data is exchanged using industry standards to protect patient information.

For more information on NANI for your hospital, please contact:

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Welcome Dr. Reasoner!

I am writing this to introduce myself as the new Iowa Chapter Champion for the Early Hearing Detection and Intervention (EHDI) program. I snatched up this opportunity to learn more about hearing impairment and deafness because of an interest that sparked in me as a child. My mother was a teacher at Iowa School for the Deaf. She taught me some signs and often included me on field trips and social events where I developed friendships with the students. At one point I even begged to attend school there, but I couldn't because I could hear. My eagerness to attach to that community has resurfaced in my role as a developmental behavioral pediatrician at the Center for Disabilities and Development (CDD), Children's Hospital of Iowa.

At the CDD, I focus on seeing young patients with neurodevelopmental disabilities, including cerebral palsy, prematurity, complex medical problems, spina bifida, Down syndrome, and other genetic disorders. I am fortunate to work with a team of specialists in our neurodevelopmental clinic so we can deliver an interdisciplinary and comprehensive evaluation and recommendations. Hearing is an important part of a child's development, and the audiologist is an important member of our team. Being able to champion for EHDI seemed like a natural extension of my professional interests.

I live in North Liberty near Coralville Lake with my husband Dan, an anesthesiologist at Mercy Iowa City, our dogs Kobi and Tino, and my cats Pounce, Gizmo, and Minnie. If this isn't crazy enough, we have 3 grown children who visit or live with us at various times; Emily (19) who just finished her first year at Luther College, Ben (23) who just graduated from Luther, and Chris (26) who is finishing up at DMACC and heading to Simpson College or ISU. Two aspire to be physicians and one loves computer science. In my spare time, I enjoy nature, reading, watching TV (who doesn't?) and traveling to beaches.



Thanks for reading my post. I look forward to hearing from you regarding any way I can be helpful in promoting awareness about early detection/monitoring of hearing loss, and appropriate interventions, including referrals to specialists and family support.

Andrea Reasoner, MD

Hospital Showcase:

...The Good & The Bad

Showcase 1:

This child was born in 2014 at a hospital and screened three times before discharged. The child did not pass any of the screenings. EHDI personnel followed up with mom after this and provided her with information on where she could go for a diagnostic assessment. The child was then screened as outpatient two months after discharge and referred again. A month later, the child now 3 months old, was rescreened again and referred. The child was rescreened three more times at 8, 11 and 15 months of age. EHDI personnel follows up with mom and shares best practice recommendations. Mom indicates she is concerned about risks related to sedation. The Follow-up Coordinator shares that it is recommended children are seen for a diagnostic assessment no later than 3 months of age to avoid sedation (this information had been given to her the first call). EHDI personnel shared that continuing to screen can lead to late identification of hearing loss. The child received a diagnostic ABR at the age of 17 months and was found to have bilateral hearing loss. The child was enrolled in early intervention at 18 months of age.



Please stress the importance to parents to go on to diagnostic assessment after the child refers at one outpatient screening and no later than 3 months of age. When parents have a difficult time following through or are hesitant to go on for diagnostic ABR testing, receiving the same consistent message from each provider they see reinforces the need for the diagnostic test. Please do not continue to rescreen children when there is not a medical need to do so. If the child refers, please refer them on for diagnostic testing.

Showcase 2:

This child was born in 2016 at a hospital. The child was screened at birth three times and did not pass. The child was brought in two weeks after discharge for an outpatient hearing screening and did not pass. An ABR was completed and the child was found to have unilateral hearing loss 23 days after birth. EHDI did not have to complete any follow up on this child as the birth hospital referred the child on for a diagnostic ABR assessment immediately following the failed outpatient screen. Hats off to them for following protocol and identifying an infant with hearing loss early!

TRAININGS:

Sharing link to NCHAM training videos (CEUs)

<http://www.infanthearing.org/ehdi-learning-center/index.html>

The Early Childhood Technical Assistance Center: Improving Systems, Practices and Outcomes for Young Children with Disabilities and their Families

<http://ectacenter.org/>

<http://ectacenter.org/portal/portal.asp>

<http://www.dec-sped.org/recommendedpractices>

EHDI Administrative Rules

Newborn Hearing Screening Law/Rules

Iowa has one of the best newborn hearing screening and reporting legislations in the United States. The legislation for newborn hearing screening provides strength for reporting, surveillance and follow up but no funding. As you may recall, effective January 1, 2004, the Iowa code and Administrative rules mandated that every newborn be screened for hearing loss prior to hospital discharge. The law further provides that any birthing facility, birth center, physician, Area Education Agency (AEA), audiologist, or other health care professional is legally required to report the following to the Iowa Department of Public Health (IDPH) within six working days: 1) the results of a hearing screen, re-screen, or diagnostic assessment 2) name of the primary care provider (PCP) that will assume responsibility for the child upon discharge and 3) risk factors associated with hearing loss for any child under age three. Essentially, the goal of universal hearing screening of all newborns and infants in Iowa is early detection of hearing loss to allow children and their families the earliest opportunity to obtain appropriate early intervention services.

The rules were amended and adopted in January 2016. The amendments further defined the roles and responsibilities of the Department and providers for infants that did not receive a newborn hearing screen or did not pass their hearing screen and require follow up; clarify who is eligible to perform hearing screens on infants and children under the age of three; added language to accommodate parental objection beyond the newborn hearing screen if their infant did not pass the hearing screen at birth; updated code citations and; the role of the advisory committee members was outlined including service, attendance and voting. The changes facilitate timely follow up for infants in need of a hearing screen, re-screen or diagnostic assessment and help avoid unnecessary contact with parents and providers. Additionally, these rule changes allow the Iowa EHDI program to monitor best practices and assist the Department in providing recommendations for improving care. All amendments were reviewed and input gathered from the EHDI advisory committee members, Iowa Board of Health, general public and the Legislative Administrative Rules Committee. Please be sure to review the amended rules to ensure compliance with hearing screening, diagnosis and compliance in reporting for children under the age of three.

<http://www.idph.iowa.gov/ehdi/laws>

Quality Improvement Corner

Parent Surveys

In February, EHDl mailed out 2,171 surveys to families to ask about their experiences with newborn hearing screening and follow up. EHDl received 23 returned surveys of the 226 mailed surveys to home birth families. There were a total of 1,945 surveys sent to hospital birth families and 147 surveys returned completed. EHDl included a link in the mailed surveys for families that wanted to complete the survey online. Analysis of the survey results will soon be complete and shared in an upcoming newsletter.

2015 Parent Surveys	Hospital Births
I knew there was a law about newborn hearing screening before my child was screened...	54%
I knew my baby was screened...	97%
I was given (verbal or/and writing) the results of my baby's hearing screen...	97%
I was told my baby would need an outpatient hearing screen after my baby did not pass the newborn hearing screen at the hospital...	77%
The hospital scheduled an appointment for the outpatient hearing screen prior to hospital discharge...	36%
When my baby did not pass the outpatient hearing screen, I was given information on where to go for a diagnostic assessment...	41%

Texting Families

EHDl has started a pilot to text families for follow up. We will continue contacting parents by phone and letter in addition to text. Since the pilot began, 87 texts have been sent to families of infants in need of hearing rescreen. Out of those, 45% responded with at least one text or a call back. The child's contact person has to confirm their identity by text before releasing any private information by texting back their date of birth, last known address and last name. When a child is in need of follow up, please mention to the contact person for the child that they may receive a text from the Iowa Dept. of Public Health so they are aware that this is a possibility. We have experienced a mainly positive and speedy response to texting by families so far. Additionally, the program is texting families of children in need of a hearing assessment after they refer at their outpatient hearing screening and piloting decline texts with families. We will continue to pilot texting families and decide later this year if this is a practice that will be incorporated in EHDl follow up protocols. After the pilot, we will send parent surveys via text to obtain more feedback. We will continue to analyze the data from the texting pilot and share more information as it is available.

BEST PRACTICES TIP

If results are entered into the EHDl database incorrectly, please contact EHDl staff to correct these results. This is imperative as EHDl staff will not know if the results are incorrectly entered until we receive this information. It is helpful to enter a note in the child's record but this alone is not enough to ensure the results are modified. The EHDl system will read the results as what it entered and not what is in the note. Please refer to our contact information at the end of the newsletter if needed.

Understanding Your Own Data

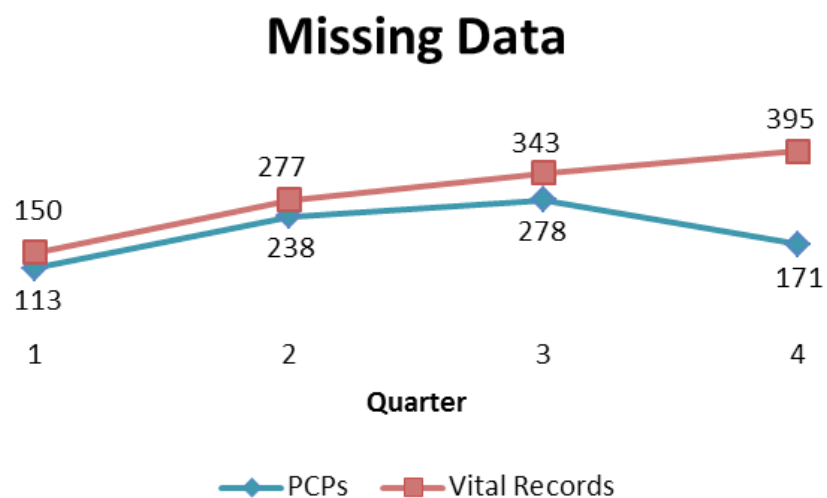
As we closed out 2014 data files, we noted an increase in the number of missing kids for that year totaled 683 records. This means that records for these children were not entered into the database and EHDl personnel had to contact the birth hospital to follow up on the child's record being entered. As you know, children's records are required to be entered into the EHDl system within 6 days of birth. This allows the IDPH to follow up with a family, if needed, in a timely manner.

In 2015, there were almost double the amount of kids that were missing from the database totaling 1,165 records. This is an even larger number of records that EHDl personnel had to contact hospitals to get children entered. Records missing from the database delays follow up for children that need it and makes it harder to meet national goals for rescreening no later than 1 month. More importantly it delays children from being identified with a hearing loss at an early age. Please make an effort to improve timely entry. If no progress is made, EHDl personnel will be in contact to set up a correction action plan.

2014		2015		2016	
January	94	January	37	January	83
February	48	February	39	February	86
March	23	March	74	March	82
April	66	April	41	April	65
May	55	May	43	May	51
June	46	June	193	June	
July	70	July	47	July	
August	49	August	137	August	
September	53	September	159	September	
October	40	October	227	October	
November	90	November	72	November	
December	49	December	96	December	
TOTAL	683	TOTAL	1165	TOTAL	367

In addition, primary care provider (PCP) information is to be collected and reported in the child's record in the database. This also assists EHDl staff with completing timely follow up on children and lowers the child's likelihood of becoming lost to follow up. Children's records are not complete (even if the child passed the newborn hearing screening) until all required information, which includes the child's PCP, is entered into the record.

In 2014, 466 PCPs were missing from children's records, a rate that almost doubled in 2015 with 800 missing PCPs. The graph below shows the total of missing PCPs that EHDl staff followed up on each quarter in 2015. There has been a steady increase in the number of missing PCPs in children's records with a total of 160 missing PCPs so far in 2016. Again, this is something that we will continue to monitor and reach out to facility contacts to create a plan to decrease the numbers of missing PCPs in children's records for their facility.



Sound Bites

Updates from the EHDI Advisory Committee Meeting on April 7, 2016.

MEETING SUMMARY

- *EHDI purchased a piece of diagnostic ABR equipment to be used in a second pilot site at an AEA for ABR testing of young infants.*
- *Hearing Aid and Audio Funding has been 100% allocated. New applications will go on the waiting list. If funding is approved by the legislature next fiscal year, the applications will be processed in the order received.*
- *EHDI has added 3 more WIC pilot sites to the WIC-EHDI pilot program.*
- *PCP and parent packets for children newly diagnosed with hearing loss was discussed. A work group has been identified to work on the creation of the parent packets.*

Next EHDI Advisory Committee Meeting:

July 7, 2016

Learning Resource Center

3550 Mills Civic Parkway, West Des Moines, IA 50265

Please allow 48 hours' notice for accommodations.

Ordering Brochures:

The NEW Iowa Newborn Screening program shared brochure for EHDI, Newborn Dried Blood Spot and Critical Congenital Heart Disease are now ready for distribution. To order the new brochure for free, contact the Iowa Healthy Families line at (800) 369-2229. Request publication IDPH131 when calling. The new brochure is not yet ready for distribution in Spanish. You can still order the old EHDI brochure in Spanish by requesting publication IDPH 131S. We will let you know once the Spanish brochure is ready!

We want to hear from you.

We value your feedback and are here to answer any questions you may encounter throughout the hearing screening and follow-up process. Below is contact information for our dedicated staff. We look forward to hearing from you.

State EHDI Coordinator

Tammy O'Hollearn
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EHDI Follow-Up/Family Support Coordinator

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